

**Children's Special Health Services
Family Advisory Council Meeting Minutes
November 19, 2005**

Present from the Family Advisory Council: Donene Feist, Jennifer Restemayer, Lisa Beckman, Cheryl Klee, Twyla Bohl, and Carla Peltier.

Present from CSHS: Kora Dockter, Sue Burns, Leann Bayman, and Tammy Gallup-Millner.

Present from the Health Department: Kim Senn.

Welcome/Introductions:

Tammy welcomed members to the meeting. The Family Advisory Council membership list will be updated to include Cheryl Klee's e-mail address.

Follow-up from August Meeting:

August 2005 meeting minutes were accepted as written. Tammy relayed that unit staff had used advice provided at the May and August 2005 meetings as documented on the Recommendation/Review Summary Sheet with the exception of promoting the new MCHB definition of family-centered care and cultural/linguistic competence. Donene relayed the definition had been included in the Family Voices newsletter and gave the suggestion that this activity should be included on the Recommendation/Review Summary Sheet.

Updates:

National Update

- MCH Block Grant budget for FFY 2006 - Currently, the Title V block grant is receiving \$700 million under a continuing resolution, which was in effect until November 18. A continuing resolution is a temporary funding mechanism to keep the government open while Congress finishes the FY 2006 appropriations bill. The Labor, HHS Appropriations bill, which funds the block grant, is now in conference to resolve the differences between the House and Senate bills. The House approved \$700 million for the Title V block grant; the Senate approved \$710 million. The FY 2005 appropriation was \$724 million, so there will definitely be less in 2006 than last year; the question that remains is how much less. For FY 2006 (10/2005 – 9/2006), the Title V block grant is expected to be \$14 to \$24 million less than what was received in FY 2005. If it is funded at the House \$700 million level, ND will lose \$62,203 in federal funds as well as state required matching funds. Together this would be a reduction of about \$110,000 for the state. Donene relayed that the Medicaid budget is also being discussed at the federal level and there is the possibility of changes with co-pays and EPSDT benefits for children. The Family Advisory Council recommended that members be notified when comments regarding the impact of cuts are being solicited at the national level.
- Association of Maternal & Child Health Programs (AMCHP) Bylaw Changes regarding Family Liaison Membership - For an additional \$105 per member, North Dakota can extend individual membership to any Title V program employee or individual that works in partnership with the Title V program. Some states have added family liaisons. Regular members can serve on AMCHP committees and task forces. Suggested changes to AMCHP

bylaws address two Family Representative positions on the Board of Directors. If members are interested in AMCHP membership, they are to notify Tammy.

- AMCHP Scholarship Opportunity for National Meeting - AMCHP awards scholarships to cover expenses for travel, lodging and conference registration for up to 15 family representatives working with Title V programs. As nominations from the MCH side of the Title V program were encouraged this year, CSHS did not contact Family Advisory Council members regarding this opportunity. Kim will follow-up to see if a family representative from the Early Childhood Alliance was solicited. Nomination forms were due 11/11/05.

Department of Human Services (DHS) Update

- DHS has a new organizational chart effective 1/1/06 that includes a cabinet in the management structure. This structure changes the number of individuals reporting directly to the Executive Director. It also moves Medicaid waivers and home and community based services to the Medical Services Division. This structure is expected to better align similar services and support visionary planning and enhanced exchange of ideas and communication. The Medical Services Division now includes two assistant director positions, one for Operations (Karalee Adam) and the other for Program (Erik Elkins).
- The Interim Budget Committee on Human Services last met on October 4, 2005. Part of the meeting focused on HCR 3054, the study of services for children with special health care needs. Tammy provided testimony regarding CSHS. Dr. Robert Wentz, Medical Advisory Council representative, provided testimony on CSHS medical eligibility. He also provided recommendations to the department after testifying a second time as a private citizen. Donene Feist provided comments regarding changes to eligibility criteria and also provided an informational CD to legislators on the committee. There were few questions and no direction was given by legislators as to future study direction. The next meeting of the Budget Committee on Human Services is December 14, 2005. Tammy was unsure of specific items that will be covered as a formal agenda has not yet been disseminated by the legislative council.
- The purpose of the Medical Needs Task Force is to get recommendations regarding a Medicaid waiver for children with extraordinary medical needs required in SB 2395 and to gather information to better understand unmet special health needs of children for the child health study required in HCR 3054. The last meeting of the Medical Needs Task Force was held 10/31/2005. Agenda items included: a legislative update and report on State Review Team activities; content to help organize the planning process (e.g.) use of technical assistance papers and discussion regarding need for a prevalence study; an EPSDT presentation; presentations by Task Force members on waiver and eligibility options from other states; and recommendations for the DHS on next steps (e.g.) data meeting which is scheduled for 11/22/05. The next full Task Force meeting will likely be in January 2006. Family Advisory Council members were asked to provide information about services potentially needed through a waiver. The following were suggested: 1) Medicaid access, 2) Respite, 3) Family Subsidy to cover what Medicaid may not cover (e.g.) Depends rather than diapers, Adaptive equipment that supports independence (e.g.) bathchairs, specialized shoes, etc., Capped items (e.g.) assure adequate number of urinary catheters are covered, and 4) Care Coordination – care coordination implies more of a partnership with families as opposed to other case management programs which are not always perceived as helpful by families.

Department of Health Update

- Kim Senn provided an oral health update. An oral health institute was held November 2005, which was attended by representatives from the Family Health Division in the Health

Department, CSHS, EPSDT, and Head Start. An action plan was developed that focused on three goals: 1) Reimbursement of fluoride varnish by medical providers, 2) Oral health education, and 3) Access (e.g.) assuring sufficient providers, loan repayment activities, locating a Community Resource Coordinator at the dental gap clinic, use of a mobile van to provide care, etc. The state has received two grants, a state oral health systems collaboration grant and a CDC grant. The CDC grant supports the Oral Health Coalition. Kim also announced that the Health Department is redoing their website and that Carol Meidinger will be retiring from the Injury Prevention & Control Division. Her last day is December 23, 2005.

CSHS Reports:

Asthma Training – Family Clip

Kora reported that a group of individuals is developing on-line web training for providers and educators to help implement SB 2163, which went into effect 8/1/2005. This law relates to students' possession and self-administration of medication for the treatment of asthma and anaphylaxis. A video clip of Don and Estelle Lawson's family's story was shown to Family Advisory Council members. This clip will be an introductory segment of the web training. Family Advisory Council members recommended the family clip be available as a stand-alone segment as well. When completed, all of the training modules will be available on the following website: www.ndhealth.gov/asthma. Family Advisory Council members recommended a brochure or fact sheet be developed. Kora relayed a "Frequently Asked Questions" e-mail could be sent out if needed. Donene offered to put relevant information out on her listserv. Kora relayed that reimbursement for asthma education provided by certified asthma educators is also being explored.

Medical Advisory Council Follow-up

Leann provided updates on progress related to the work plan developed in response to Medical Advisory Council recommendations from the May 2005 meeting. Conditions that may require neuropsychological coverage have been identified and provider board certification requirements are being determined. Use of the new condition grid has been initiated on a trial basis with some challenges. Both allergy shots and allergy medications will be covered as will pneumovests for children with cystic fibrosis. Information about use of the vests for additional conditions is being explored. Supplemental formula has been covered but staff are finding gaps in coverage by primary payers (e.g.) Medicaid, WIC, etc.

State Strategic Plan Results

The CSHS State Performance Measure handout was reviewed. Tammy highlighted the following measures:

- An important result measure was determined through a telephone survey - 100% of individuals/families served by CSHS reported services received met their needs
- Numbers served - unduplicated # served = 1,239, toll-free calls received = 1,566, # of individuals who received health information = 1,073
- Efficiency measures – timeframes were well-met on various measures with results at 90% or greater
- Systems - improvements noted for care coordination in a medical home, transition, family participation, health coverage, screening, asthma, and data access
- New measure was added – assessment and planning for children with extraordinary medical needs

Family Advisory Council members discussed the best location for care coordination providers and suggested the following.

- Locate staff at local clinics so funding and service reimbursement is linked/better addressed
- Multidisciplinary clinic staff, both in-state and out-of-state, help coordinate care; also link to local public health staff
- Rural areas lack providers so location of care coordinators should depend on structure of the community
- Community Resource Coordinators may have a role
- Put public health care coordinators in a clinic setting
- Clinic social work staff not always helpful; need care coordinators with more specialized medical knowledge

County Training Event

Health Tracks and CSHS conducted a joint annual training on October 25-26, 2005. Evaluations returned were very positive. Topics covered included Health Tracks 101, Methamphetamine, Genetics, Mental Health Screening, Denver Developmental Screening, Physical Assessment of Children, Dental/Orthodontic Screening, CSHS Program Update, Muscular Dystrophy, and a family presentation by Bonnie and Mark Solberg, the Muscular Dystrophy Association Ambassador family from Grand Forks. CSHS also sponsored a “New Worker Training”, the evening of October 25th, which six county staff attended.

Metabolic Issue – Convenience Food Requests

Currently, CSHS provides formula to 21 clients. Input was solicited from Family Advisory Council members regarding provision of the following metabolic products:

- Vitaflo PKU Express - a gel alternative to traditional powdered formula. The volume consumed would be less than with traditional formula. Individuals may also want flavoring for the gel, which is extra. CSHS opted not to offer this product because of the extremely high cost per month.
- PhenylAde 40 - a pre-measured pouch of traditional powdered formula. New flavors are offered, which are different than those available in the canned PhenylAde. CSHS opted not to order this product as it was determined to be merely a convenience option.
- Phenex Chews - a chewable tablet rather than liquid formula. If all clients currently using Phenex-2 switched to Phenex Chews, the price difference would be significant for CSHS. Staff opted to provide on a case-by-case basis only.
- Low protein modified food products provided to Medicaid clients - CSHS has requested that at least 50% of the total order be comprised of staples such as breads, pastas, and rice.

Family Advisory Council members provided the following comments:

- Can families pay what is “over” the regular cost?
- Ask businesses for discounts and relay products won’t be offered if cost is not adjusted.
- Members generally agreed that a practical approach is not unreasonable and that pre-measured pouches are unnecessary.

Other Reports:

Donene provided information from Family Voices for the committee to review. Included was the publication entitled *Accessing Healthcare* and various fact sheets. These materials are available on the Family Voices website.

Next Meeting:

The next meeting will be held Saturday, February 18, 2006 from 9:00 – 12:00 noon.